

# Public Involvement in Research:

## Ways of Building Partnerships

By Jack Nunn

### Monash Comprehensive Cancer Consortium

#### What is public involvement in research?

The National Health and Medical Research Council defines involvement as:

**“research being carried out with or by consumers and community members rather than to, about or for them.”<sup>1</sup>**

But there’s a word in there that I don’t use. ‘Consumer’. This word for me does not imply an equal partnership. I prefer saying ‘the public’ or even ‘people’. The Health Research Authority in England came up with what I think is the best description of ‘the public’:

“When we use this term public means patients, potential patients or members of the public including those with known genetic dispositions, carers and people who use health and social care services as well as people from organisations that represent people who use health and social care services.”<sup>2</sup>

It is important to explore these different terms. Do you really need ‘patient’ involvement, or just someone to check it is in plain English – or do you need someone with a very specific experience or condition to help inform your work.

It is very important to reflect on the tasks that you will be asking people to do – and what skills, experience or knowledge that person might require. In addition, it’s very important to always consider what support they might need. This might be learning and development, financial or emotional support – perhaps a buddy or mentor.

---

<sup>1</sup> <https://consultations.nhmrc.gov.au/files/consultations/drafts/draftconsstatementconsultationversion140807.pdf>

<sup>2</sup> <http://www.hra.nhs.uk/documents/2013/10/hra-public-involvement-strategy-circulation-september-2013.pdf>

# Which stage of the research cycle?

INVOLVE have a page which describes how you can involve people at each stage of the research cycle:

<http://www.invo.org.uk/posttypesresource/where-and-how-to-involve-in-the-research-cycle/>

From identifying topics, prioritisation, to funding, designing trials (improving recruitment), analysing data, dissemination and even translation.

## Who says?

The National Health and Medical Research Council “Revised Statement on Consumer and Community Involvement in Health and Medical Research statement” says:

**“Active involvement of consumers and community members in health and medical research benefits the quality and direction of research.** The vision for the Statement is: Consumers, community members and researchers will work in partnerships based on understanding, respect and shared commitment to research that will improve the health of all Australians. Consumer and community involvement is about research being carried out with or by consumers and community members rather than to, about or for them. It includes consumers and community members working with research funders to prioritise research, being involved in grant funding processes and providing advice as members of project steering groups. This is distinct from people who are the participants in research projects”<sup>3</sup>

A recent review of public involvement by the National Institute for Health Research recommends that ‘relevance’ be one of the three measures of success of future public involvement in health and social care research.<sup>4</sup>

What is relevance? **‘questions that reflect the interests and needs of patients, carers and clinicians’**<sup>5</sup>

A recent paper about involvement concluded that best-practice is to “Involve early - Patient input is often most impactful in the project formation phase. Researchers tend to have a focus on scientific questions and less on the wider context of disease. Patients can bring the perspective of what it is like to live with a disease, or several diseases/comorbidities...By having patient organisations, and their patients, as funded partners, a patient perspective was incorporated into even the earliest drafts of the project proposal and work plan”<sup>6</sup>

A report from the National Institute for Health Research stated:

“public involvement in research has had a variety of impacts, including impact on the research (at all stages and levels), on the members of the public who were involved, on the researchers, on participants, on community organisations and the wider community. It has also influenced whether the results of research have been used to bring about change.”<sup>7</sup>

---

<sup>3</sup> <http://consultations.nhmrc.gov.au/files/consultations/drafts/draftconsstatementconsultationversion140807.pdf>

<sup>4</sup> <http://www.nihr.ac.uk/get-involved/Extra%20Mile2.pdf>

<sup>5</sup> <http://www.researchinvolvement.com/content/1/1/2>

<sup>6</sup> <http://www.researchinvolvement.com/content/1/1/5>

<sup>7</sup> [http://www.invo.org.uk/wp-content/uploads/2011/11/Involve\\_Exploring\\_Impactfinal28.10.09.pdf](http://www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf)

# Funding

There's a mismatch between research the public want done, and the research that gets funded.

I observed the James Lind Alliance<sup>8</sup> priority setting partnership with the MS society. Watching researchers and people affected by MS compare priorities was very interesting. As a result of this kind of work, the MS Society shifted their funding focus to curing and living with, rather than just curing.

A recent paper about the kind of research that gets funded stated that “In JLA PSPs, drugs accounted for only 18 % (23/126) of the treatments mentioned in priorities; in registered non-commercial trials, drugs accounted for 37 % (397/1069) of the treatments mentioned; and in registered commercial trials, drugs accounted for 86 % (689/798) of the treatments mentioned.”<sup>9</sup>

Just to pre-empt – this is not an attack on ‘blue sky’ research, or research that is done, even though we don’t know where it will lead. No one could have predicted the World Wide Web would emerge from CERN and who knows what new diagnostic techniques could emerge from the Large Hadron Collider – we need that kind of science.

Funders are also increasingly looking for examples of public involvement in grant applications. The National Institute for Health Research in England was the first large health research funder in the world to do this and it has set an example which is slowly being followed. For example, in Australia, Cancer Australia now ask for evidence of involvement in a grant application.

As one journal article recently stated: “Close and regular dialogue can help researchers to consider these outcomes and to prepare intelligible lay summaries of their research that will help generate realistic timescales and avoid exaggerated forecasts of impact. This, in turn, may assist in their applications for funding.”<sup>10</sup>

---

<sup>8</sup> <http://www.lindalliance.org/>

<sup>9</sup> <http://www.researchinvolvement.com/content/1/1/2>

<sup>10</sup> <http://www.researchinvolvement.com/content/pdf/s40900-015-0002-y.pdf>

# Attitudes

Sometimes a change in attitude involves individuals reflecting on assumptions and actively challenging these.

Here are some helpful quotations that sum up some attitudes, taken from papers recently published in the new journal 'Research Involvement and Engagement':

- "There is a perception that patients either will not understand or would not be interested in the day-to-day operations of a research project. This often means that patients are given simplified and inaccurate explanations of how a project is progressing, what the challenges are and what the results mean. In reality, the more patients are involved in the day-to-day activities of the project, and the more they are informed about its progress, the more they can understand, contribute and positively impact."<sup>11</sup>
- Academic culture can often be very different from that of other spheres of work, and bringing lay representatives into the research arena helps to raise awareness of issues outside the academic culture box. This is particularly useful where researchers have moved through first and second degrees into doctorates and post-doctoral research in basic science. Lay members are more focussed on the practical aspects and outcomes of research and how it can affect patients and carers."<sup>12</sup>
- "The idea of patient involvement can be difficult for researchers as it does not adhere to the traditional "scientific method". The experiential knowledge of patients and the public, according to some, lacks the objectivity, verifiability, universality and rationality of scientific knowledge. However, it is now increasingly appreciated among researchers that patients' knowledge and experience is valuable for research and contributes to increasing the quality, relevance and appropriateness of research processes"<sup>13</sup>
- "A key feature of our model is that all research projects running through our facility are receiving involvement from a wide range of lay members. Individual lay members may get involved at a deeper level in specific projects, but they have broad involvement in everything that we do which means that on a monthly basis, there is always an opportunity for researchers and lay members to share opinions and ideas. This differs from many PPI models where individual projects are allocated one or two lay members whose involvement may go through peaks and troughs."<sup>14</sup>
- "Actually, it's surprising that it has taken us this long to focus on patient engagement because the results we have thus far are nothing short of astounding. If patient engagement were a drug, it would be the blockbuster drug of the century and malpractice not to use it." *Leonard Kish—Principal and Co-Founder of VivaPhi*<sup>15</sup>

---

<sup>11</sup> <http://www.researchinvolvement.com/content/1/1/5>

<sup>12</sup> <http://www.researchinvolvement.com/content/pdf/s40900-015-0002-y.pdf>

<sup>13</sup> <http://www.researchinvolvement.com/content/1/1/4>

<sup>14</sup> <http://www.researchinvolvement.com/content/1/1/3>

<sup>15</sup> <http://www.researchinvolvement.com/content/1/1/4>

# Examples of involvement in lab research

Public involvement in lab research does require more imagination sometimes. Here examples of approaches, some of them very imaginative.

- **Learning and development for the public and patients.** [Building Research Partnerships](#) – shared learning for the public and researchers about public involvement and how to do it, is a model identified as best-practice in Europe. From these short one day events, relationships would develop and conversations would start. [Here is a poster](#) about the long term impact of this project. All resources are free and open access under Creative Commons.
- I've mentioned the [James Lind Alliance](#) already and it's really worth looking into this innovative model to help understand how the public can be involved at that essential stage of identifying topics and prioritising.
- I observed the Royal Brompton hospital run a '**Cafe scientific**' – it's an informal setting where scientists are invited to talk in laymen's terms about their work in a topical. There are many ways of doing it, but the events aim for an informal and friendly atmosphere, and are believed to improve the image of scientists and careers in science. Wikipedia says 'Cafe Scientifique aims to demystify scientific research for the general public and empower non-scientists to more comfortably and accurately assess science'. It's a space for people to ask and think – in all directions.
- **Research Buddies** - there are many variations on this, but essentially it is having members of the public, often people affected by a condition, paired with researchers helping motivate and enthuse them about their work. WEHI has this system in place and is looking to expand it.
- **Groups and committees** - members of the public can be supported to be a part of all discussions – with learning and development and support (financial/emotional), everyone can be involved.
- **Dissemination** - the public can help with disseminating results from lab research. The two previous projects could support lay people to be able to talk with researchers and about their research, and go to their community, online, or other settings to share results.
- **Interpretation of data** – Open access and linked-data. You can publish data for anyone to interpret - what more powerful way is there to share your research than to share your data with everyone? [Genes in space](#), [Eyewire](#), [Cell slider](#) – these are not within everyone's budget, but are hugely imaginative ways to harness the pattern spotting power of the brain - using our brains as a distributed network of computers.
- **Biobanking** – Having members of the public and donors involved at every level, including a 'lay steering committee....who are themselves donors' results in 'a proportion of the participants being engaged in dynamic consent' which is more practical. 16

---

<sup>16</sup> <http://www.researchinvolvement.com/content/1/1/3>

Thank you to Bec Hanley and Anna Kilgour for their assistance in compiling this list.

# What can you do now?

- **Talk to people**
  - Find out what's going on - anyone doing anything similar?
  - Anyone want to work with you to start something yourself
- **Find support**
  - Does your organisation have funding for involvement? Could it need more?
  - Are there external organisations who can support, or individuals who can play a role in leading your organisation in this way of working?
  - Once you think you know what you want to do and where you need support, there are many people willing to give their time and expertise to projects, you only have to open your door and ask.
- **What do you want to do?**
  - Where do you want to involve people? Research prioritisation, research methodology review (e.g. human ethics applications), research reference group (e.g. review grants), research buddies, friends of the lab, public spokespersons for the importance/relevance of your research, helping disseminate.
  - What tasks will people have? Be specific and realistic, what are the commitments? Ask people for feedback on what you want them to do!
  - What support might they need? Learning and development, financial or emotional support – perhaps a buddy or mentor?
  - What type of involvement? Who might you unintentionally exclude? (committees, research buddies, friends of the lab, online, face to face, evening/day time? Paid/unpaid? Commitment short term or long term)
- **Make a plan:** How would your involvement be structured? (cross-organisational level, institutional level, department or lab, by project or with a collaborative tumour stream group)
- **What resources or support do you need?** Internal support from colleagues? External organisations or expertise for recruitment and training? Budget – see 'Budgeting for involvement'<sup>17</sup>
- **Do something, start early**
  - Even if it's a small, one-off event with some biscuits and a small group of people, you never know where it could lead.
- **Evaluate it, measure the impact.** Planning evaluation and impact assessment into your involvement ensures you can learn from experiences, improve and share your learning with others. It hopefully means we generate a larger evidence base for the benefits of involvement and best-practice.

---

<sup>17</sup> <http://www.invo.org.uk/posttypepublication/budgeting-for-involvement/>

# Resources

- Building Research Partnerships:
  - Here is a [poster](#) about the impact of involvement in research and shared learning events for the public and professionals.
  - [Here](#) is a report about the impact of the work
  - Here are the resources for free: [www.macmillan.org.uk/researchlearning](http://www.macmillan.org.uk/researchlearning) (page 64- 66 to help with planning involvement)
- [Here](#) is the NMHRC draft statement on 'Consumer and Community Involvement in Health and Medical Research'. [Here](#) is the Health Issues Centre response to this.
- <http://www.involvingpeopleinresearch.org.au/>
- INVOLVE resource about '[Budgeting for involvement](#)'
- National Institute for Health Research 2015 [report](#) about their public involvement strategy so far, and next steps.
- New journal – 'Research Involvement and Engagement' [www.researchinvolvement.com/](http://www.researchinvolvement.com/)